Copyright 1988 by the New York State Association for Retarded Children, Inc., 393 Delaware Avenue, Delmar, New York 12054

All rights reserved. Printed in USA

I am delighted to learn that the Board of Governors of the New York State Association for Retarded Children, Inc. has voted to support the "Medicaid Home and Community Quality Services Act." Your endorsement will certainly enhance the chance that this legislation will pass in the near future. We must strive to make the nation's Medicaid System responsive to the goals that we as a nation have set for people with developmental disabilities.

I look forward to a continued, positive relationship with the Association on issues vital to those with disabilities.

Sincerely,

Senator John Chafee

Current Co-sponsors — August 10, 1988

'Medicaid Home and Community Quality Services Act of 198" S.1673 (48 co-sponsors) and H.R.3454 (193 co-sponsors)

ALABAMA

Sen. Richard Shelby (D) Sen. Howcll Heflin (D) Rep. Tom Bevill (D) Rep. Ben Erdreich (D) Rep. Claude Harris (D)

ALASKA (full delegation) Sen. Ted Stevens (R) Sen. Frank Murkowski (R) Rep. Don Young (R)

ARIZONA

Rep. John Rhodes (R) Rep. Morris Udall (D)

ARKANSAS

Sen. David Pryor (D)(1)

CALIFORNIA

Sen. Alan Cranston (D)
Rep. Tony Coelho (D)
Rep. Matthew Martinez (D)
Rep. Victor Fazio (D)
Rep. Don Edwards (D)
Rep Duncan Hunter (R)
Rep. Ronald Dellums (D)
Rep. Jim Bates (D)"(2)
Rep. Tom Lantos (D)
Rep Ron Packard (R)
Rep. Nancy Pelosi (D)
Rep. Barbara Boxer (D)

COLORADO

Sen. Timothy Wirth (D)
Rep. Hank Brown (R)
Rep Ben Nighthorse Campbell (D)
Rep. David Skaggs (D)
Rep. Daniel Schaefer (R)"
Rep. Patricia Schroeder (D)

Sen. William Armstrong (R)'

CONNECTICUT (full delegation)
Sen. Lowell Weicker (R) Sen.
Christopher Dodd (D) Rep. John
Rowland (R) Rep. Bruce Morrison
(D) Rep. Nancy Johnson (R) Rep.
Barbara Kennelly (D) Rep.
Christopher Shays (R) Rep. Sam
Geidenson (D)

DELAWARE

Sen. Joseph Biden (D) Rep. Thomas Carper (D)

DISTRICT OF COLUMBIA

(full delegation) Del. Walter Fauntroy (D)

FLORIDA

Sen. Lawton Chiles (D)
Rep. Lawrence Smith (D)
Rep. Earl Hutto (D) Rep.
Connie Mack (R) Rep Bill
Grant (D) Rep. William
Lehman (D) Rep. Claude
Pepper (D) Rep. Bill
Nelson (D)

GEORGIA

Sen. Sam Nunn (D) Sen. Wyche Fowler, Jr. (D) Rep. Charles Hatcher (D) Rep. J. Roy Rowland (D) Rep. George Darden (D) Rep. John Lewis (D)

Rep. Robert Lindsay Thomas (D)

Rep. Ed Jenkins (D)

HAWAII (full delegation) Sen. Daniel Inouye (D) Sen. Spark Matsunaga (D)' Rep. David Akaka (D) Rep. Patricia Saiki (R)

IDAHO

ILLINOIS

Rep. Cardiss Collins (D)(2) Rep. Charles Hayes (D) Rep. Kenneth Gray (D) Rep. Jack Davis (R) Rep. Sidney Yates (D)

INDIANA

Rep. Lee Hamilton (D) Rep. Jim Jontz (D) Rep. Peter Visclosky (D) Rep. Andrew Jacobs (D) Rep. Frank McCloskey (D)

IOWA

Sen. Tom Harkin (D) Rep. Dave Nagle (D) Rep. Neal Smith (D)

KANSAS

Sen. Robert Dole (R)(1) Rep. Dan Glickman (D) Rep. Jan Meyers (R)

KENTUCKY

Rep. Carroll Hubbard. Jr. (D)

LOUISIANA

MAINE

Sen. George Mitchell (D)'(1) Rep. Olympia Snowe (R) Rep. Joseph Brennan (D)

MARYLAND (full delegation) Sen. Paul Sarbanes (D) Sen. Barbara Mikulski (D) Rep. Kweisi Mfume (D) Rep. Benjamin Cardin (D) Rep. Steny Hoyer (D) Rep. Constance Morella (R) Rep. Helen Bentley (R) Rep. Roy Dyson (D) Rep. Beverly Byron (D) Rep. Thomas McMillen (D)

MASSACHUSETTS

Sen. John F. Kerry (D) Rep. Nicholas Mavroules (D) Rep. Brian Donnelly (D) Rep. Joe Moakley (D) Rep. Chester Atkins (D) Rep. Gerry Studds (D)

MICHIGAN

Sen. Donald Riegle (D)'(1)
Rep. Paul Henry (R) Rep.
John Conyers (D) Rep.
George Crockett (D) Rep.
Guy Vander Jagt (R) Rep.
Fred Upton (R) Rep. Bill
Schuette (R) Rep. Howard
Wolpe (D) Rep. Robert Davis (R) Rep. Dale Kildee (D)
Rep. William Ford (D) Rep.
Dennis Hertel (D) Rep.
William Broomfield (R) Rep.
Bob Traxler (1)) Rep. Carl
Pursell (R) Rep. David
Bonior (I))

MINNESOTA

Rep. James Ohcrsiar (I) Rep. Martin Sabo (D) Rep. Timothy Penny (I)) Rep. Arlan Strangeland (R) Rep. Bruce Vento (D) Rep. Gem Sikorski (D)" (2)

MISSISSIPPI

MISSOURI

MONTANA

Sen. Max Baucus (1))'(1)
Rep. Pat Williams (I)) Rep.
Ron Marlcnec { R)

NEBRASKA

NEVADA

Sen. Chic Hecht (R)

NEW HAMPSHIRE

Sen. Gordon J. Humphrey (R) Rep. Robert C. Smith (R) Rep. Judd Gregg (R)

NEW JERSEY (full delegation)

Sen. Bill Bradley (D)'(1) Sen. Frank Lautenberg (D) Rep. James Florio (D)"" Rep. Dean Gallo (R) Rep. Robert Roe (D) Rep. Bernard Dwyer (D) Rep. Peter Rodino (D) Rep. James Courier (R)

Rep. William Hughes (D)
Rep. Matthew Rinaldo (R)

Rep. Frank Guarini (D) Rep. Robert Torricelli (D) Rep. Christopher Smith (R)

Rep. Marge Roukema (R) Rep. Jim Saxton (R)

NEW MEXICO

Sen. Jeff Bingaman (D) Rep. Bill Richardson (D)"

NEW YORK

Sen. Daniel Moynihan (D)'
Rep. Ted Weiss (D)
Rep. Robert Garcia (D)
Rep. Charles Rangel (D)
Rep. George Wortley (R)
Rep. Mario Biaggi (D)
Rep. Benjamin Gilman (R)
Rep. Sherwood Boehlert (R)
Rep. Major Owens (D)
Rep. Edolphus Towns (D)
Rep. Robert Mrazek (D)
Rep. Thomas J. Manton (D)

NORTH CAROLINA

Rep. Walter Jones (D) Rep. Alex McMillian (R) Rep. David Price (D) Rep. James Clarke (D)

NORTH DAKOTA (full delegation) Sen. Kent Conrad (D) Sen. Quentin Burdick (D) Rep. Byron Dorgan (D)

оню

Rep. Tony P. Hall (D) Rep. James A. Traficant (D) Rep. Edward Feighan (D) Rep. Mary Rose Oakar (D) Rep. Marcy Kaptur (D) Rep. Douglas Applegate (D) Rep. Thomas Luken (D)" Rep. Bob McEwen (R) Rep. Donald Lukens (R) Rep. Donald Pease (D)

OKLAHOMA

OREGON

Sen. Mark Hatfield (R) Rep. Ron Wyden (D)"(2) Rep. Peter DeFazio (D)

PENNSYLVANIA

Sen. Arlen Specter (R) Rep. Joseph Kolter (D) Rep. Curt Weldon (R) Rep. William Coyne (D) Rep. Doug Walgren (D)"(2) Rep. Thomas Ridge (R) Rep. Thomas Foglietta (D) Rep. Peter Kostmayer (D) Rep. Gus Yatron (D)

RHODE ISLAND (full delegation)

Sen. John Chafee (R)'(1) Sen. Claiborne Pell (D) Rep. Fernand St. Germain (D) Rep. Claudine Schneider (R)

SOUTH CAROLINA

Sen. Ernest Hollings (D) Sen. Strom Thurmond (R) Rep. John Spratt (D) Rep. Arthur Ravenel (R) Rep. Elizabeth Patterson (D) Rep. Robin Tallon (D)

SOUTH DAKOTA

Sen. Thomas Daschle (D)' Rep. Tim Johnson (D)

TENNESSEE

Sen. Albert Gore (D)
Rep. Jim Cooper (D)"
Rep. Marilyn Lloyd (D)
Rep. Harold Ford (D)
Rep. Bob Clement (D)

TEXAS

Rep. Henry Gonzales (D)
Rep. Martin Frost (D) Rep
Beau Boulter (R) Rep. Ron
Coleman (D) Rep. Albert
Bustamonte (D) Rep. Jim
Chapman (D) Rep. Charles
Wilson (D) Rep. Steve
Bartlett (R) Rep. Solomon
Ortiz (D) Rep. Charles
Stenholm (D) Rep. John
Bryant (D)" Rep. Mickey
Leland (D)"(2) Rep. Kika de
la Garza (D) Rep. Richard
Armey (R) Rep. Marvin Leath
(D)

UTAH (full delegation) Sen. Orrin Hatch (R) Sen. Jake Garn (R) Rep. Howard Nielson (R)" Rep. Wayne Owens (D) Rep. James Hansen (R)

VERMONT (full delegation) Sen. Patrick Leahy (D) Sen.

Robert Stafford (R) Rep. James Jeffords (R)

VIRGINIA

Rep. Frank Wolf (R)

WASHINGTON

Sen. Brock Adams (D) Sen. Daniel Evans (R) Rep. Thomas Foley (D) Rep. Norman Dicks (D) Rep. Mike Lowry (D) Rep. Don Bonker (D) Rep. John R. Miller (R)

WEST VIRGINIA

Sen. John D. Rockefeller. IV (D)'(1) Rep. Nick Rahall (D) Rep. Harley Staggers (D) Rep. Bob Wise (D)

WISCONSIN

Rep. Les Aspin (D)
Rep. Robert Kastenmeier (D)
Rep. Jim Moody (D)
Rep. Steven Gunderson (R)

WYOMING

Sen. Malcolm Wallop (R)"

'Member of Senate Finance Committee '(1) Member of Subcommittee on Health

Member of House Energy and Commerce Committee

"(2) Member of Subcommittee on Health and the Environment

Preface

Since the events that led to the signing of the Willowbrook Consent Decree almost 14 years ago, New York State has often served as a national stage for discussion and debate regarding issues of importance to persons with mental retardation and developmental disabilities. This monograph continues our Association's role as an active participant in this process; a process which so intimately affects the lives of so many of our organization's 57,000 members. It also makes it clear that despite any indication to the contrary, there is enormous grassroots support in our State for legislation of unprecedented significance to persons with mental retardation and developmental disabilities.

Finally, we do not intend that this monograph be a complex analytical work; nor is our sole aim to provide an overview of a specific piece of federal legislation. Rather our greatest wish is that this monograph clearly articulate our Association's position on a broad conceptual issue; an issue which will undoubtedly continue to be important irrespective of the fate of any one solution that has been or will be devised to resolve it.

Contents

Preface3	
Introduction	4
The Need for Medicaid Reform5	
Legislative Summary: What Does the "Medicaid Home and Community Quality Services Act" Do?6)
Other Features: A Philosophy Which Promotes Comprehensive Community Care and Values the Needs and Worth of Individuals Who Are Disabled and Their Families	}
The Political Debate Over the "Chafee Bill"	9
Conclusion14	4
Appendix	,

4

n 1988 in New York
State, approximately
10,000 individuals
continue to
reside in large
and
depersonalized
State institutions;
another 10,000 persons
living at home are in
desperate need of community residential
placement."

Introduction

The New York State Association for Retarded Children, Inc. (NYSARC) was founded in 1949 by a group of parents of children with mental retardation and other individuals concerned with the well-being of these persons. The founding premise of the Association was that persons with mental retardation are best served in homelike community-based settings and that traditional institutional approaches to rendering care were cruel, debilitating and unnecessary.

Since 1949, NYSARC has emerged as perhaps the largest and most effective not-for-profit provider and grass-roots advocacy organization of its kind in the nation. The Association's 65-member chapters operate hundreds of day and community-based residential programs throughout New York State. Further, the Association has continued its tradition of advocating on issues of statewide and national importance; a tradition which has flourished throughout the administrations of five of New York's Governors and which has resulted in the signing of landmark legislation establishing the basis for a vast system of community-based care.

The growth of our Association as a service provider has reflected the dramatic growth of community-based services on both a state and national level. In New York. State there are now approximately 20,000 persons in community residential programs; another 35,000 attend community-based day programs. Clearly, we have come a long way since the days when institutionalization was seen as the only recourse for persons with mental retardation and developmental disabilities.

However, as an advocacy organization, NYSARC must constantly ask itself what else remains to be done to insure that the rights and well-being of all persons with mental retardation are protected and enhanced. In this respect, we are confronted with the fact that our goal of establishing appropriate community-based services for all of these persons who are disabled is far from complete.

In 1988 in New York State, approximately 10,000 individuals continue to reside in large and depersonalized State institutions; another 10,000 persons living at home are in desperate need of community residential placement. This need is reflected across the nation despite over a decade of dramatic progress towards providing appropriate community-based services.

The Need for Medicaid Reform

The backbone of the developmental disabilities service system throughout the nation is the Medical Assistance Program (Medicaid) established pursuant to Title XIX of the Social Security Act. Since the early 1980's advocates throughout the State and nation have increasingly pointed out that Medicaid discourages rather than encourages the growth of community-based services. These advocates point to the restrictive nature of Medicaid regulations which limit the use of Medicaid dollars primarily to institutional services while prohibiting the expenditure of such funds on the broad array of community-based services. They ask: how can there be such a blatant contradiction between nationally accepted treatment goals and funding policies for persons with developmental disabilities?

This appears to be an obvious question. For over a decade we have come to emphasize the need for a broad range of community-based programs suited to a wide variety of individual needs. We know, for example, that there must be competitive and supported work opportunities for some individuals while other persons may require day treatment. We have also come to the realization that all individuals can live in a variety of community residential options of varying intensity.

For over a decade we have worked to build a system based on this perspective. We have pursued this goal despite our heavy reliance on Medicaid which, in fact, is used almost exclusively to provide a narrow range of highly restrictive services. In 1988 almost 70% of the funding for developmental disabilities services in New York State will come from Medicaid. Approximately 65% of these dollars will pay for institutional care. The balance of Medicaid funding will pay for the most intensive and restrictive community-based services including day treatment and small ICF/MRs.

Clearly, funding and services have been pulling in opposite directions. This conflict between service goals and funding guidelines within our own state is experienced across the nation and, as a consequence, so is the call for Medicaid reform. The broad national attention focused on Senator John Chafee's legislation (R-Rhode Island), the "Medicaid Home and Community Quality Services Act," reflects this phenomenon. So does the emerging focus on Medicaid reform legislation sponsored by Representative Henry Waxman (D-California). In New York State, the Office of Mental Retardation and Developmental Disabilities (OMRDD) own "Medicaid Waiver" is another attempt to reform Medicaid funding for developmental disabilities services. All of these proposals are intended to broaden the ability to use Medicaid to pay for a wide variety of community-based services aimed at meeting the wide variety of individual needs.

NYSARC has endorsed the proposal advanced by Senator Chafee. We feel that this proposal offers the best opportunity to overhaul an archaic national funding policy and make it consistent with the philosophy of community-based care which we have come to embrace on behalf of persons with developmental disabilities. It is the goal of this paper to explain our reasons for this position and in doing so to hopefully promote the enactment of this important and potentially landmark piece of legislation as well as the invaluable philosophical concept of Medicaid reform which it embodies.

Clearly, funding and services have been pulling in opposite directions. This conflict between service goals and funding guidelines within our own state is experienced across the nation and, as a consequence, so is the call for Medicaid reform."





he fundamental aim of the "Medicaid Home and Community Quality Services Act", also known as the 'Chafee Bill', is to maximize the availability of community-based programming for persons with developmental disabilities while minimizing reliance on large institutions to care for these individuals."



Legislative Summary:

What does the "Medicaid Home and Community Quality Services Act" Do?

The fundamental aim of the "Medicaid Home and Community Quality Services Act", also known as the "Chafee Bill", is to maximize the availability of community-based programming for persons with developmental disabilities while minimizing reliance on large institutions to care for these individuals. This goal is philosophically rooted in the notion which has been endorsed by our Association and other advocates throughout the nation: that persons who are disabled are best served in the community and that institutional care is a system of the past. The legislation sets out to accomplish this goal in two ways.

Firstly, the "Medicaid Home and Community Quality Services Act" would vastly expand the array of community-based services paid for by Medicaid to include many services not currently covered. At a minimum these services would include the following: independent case management; individual and family support services (including respite and attendant care); specialized vocational services (including prevocational services and supported employment services); protection and advocacy services; and protective intervention services.

In addition, states would, on an optional basis, be able to offer any of the following services under their state Medicaid plans: habilitation services; case coordination services; educationally-related services; occupational therapy; physical therapy; speech therapy; non-aversive behavior intervention therapy; diagnostic and assessment services; personal assistance and attendant care services; homemaker and chore services; adaptive equipment and adaptation of vehicles and housing; home health services; dental services; rehabilitation services; crisis intervention; specialized training for families and caregivers; special transportation services; personal guidance, supervision and representation; preventative services; and such other services proposed by a state and approved by the Secretary of Health and Human Services.

Secondly, the "Medicaid Home and Community Quality Services Act" would minimize a state's reliance on large institutions by capping federal financial participation for residential facilities serving 16 or more individuals (for example: all developmental centers, other ICF/MRs and SNFs). The cap would be fixed at the level of federal funds received by a state for these facilities during the year of the bill's enactment. However, the cap could be exceeded to cover inflationary increases over 6% (based on the Consumer Price Index) and to pay costs incurred by a state to comply with federal certification requirements related to an approved reduction plan.

Again, the point of this provision is to encourage states to minimize their reliance on the utilization of institutional care for persons with developmental disabilities.

It should be noted that although the "Medicaid Home and Community Quality Services Act" substantially increases the availability of federal funds for community-based services, it would prohibit the state from decreasing its funding for these services. Specifically, the hill contains a maintenance of financial effort requirement. This

requirement mandates that the state expend from non-federal funds at least the amount it expended on Community and Family Support Services prior to the enactment of the "Medicaid Home and Community Quality Services Act". Further, the bill requires the state to annually adjust its maintenance of financial effort for inflation as measured by the Consumer Price Index.

The impact of this provision is important. It means that since the state's financial contribution must be maintained, the infusion of new federal dollars necessarily means that total funding for Community and Family Support Services must increase under the "Chafee Bill". In those states where there are already substantial service levels funded entirely through state dollars, and these services would qualify for Medicaid under the "Chafee Bill", such overall funding increases could be dramatic.

Finally, the "Chafee Bill" would provide services to persons living at home without regard to family income. Under current law Medicaid generally requires that persons living at home be placed out of home in order to qualify for Medicaid funded services. This often creates an incentive to unnecessarily institutionalize individuals who would be far better served at home with their family. The "Chafee Bill" once and for all removes this incentive which is entirely inconsistent with contemporary treatment philosophy.

he 'Chafee Bill' would provide services to persons living at home without regard to family

[income."

his legislation does not simply liberalize the use of Medicaid funding for more appropriate community services; more to the point it imparts an important philosophy of care which requires services to be founded upon the need of persons who are mentally retarded to be a vital part of both their community and their family."



Other Features

A Philosophy which Promotes Comprehensive Community Care and Values the Needs and Worth of Individuals Who are Disabled and Their Families

The philosophical importance of the "Chafee Bill" in the context of Medicaid reform must be underscored. This legislation does not simply liberalize the use of Medicaid funding for more appropriate community services; more to the point it imparts an important philosophy of care which requires services to be founded upon the need of persons who are mentally retarded to be a vital part of both their community and their family. It is this philosophy which, as this paper has already established, has been adopted and accepted by almost everyone involved in caring for these individuals, but which is yet to be incorporated into the fabric of the Medicaid program. It is this gaping inconsistency between funding and philosophy which the "Medicaid Home and Community Quality Services Act" finally resolves.

Through the enactment of the "Medicaid Home and Community Quality Services Act", the federal government would set forth the framework for effectuating a national philosophy within which states would be encouraged to provide appropriate care. Such framework and its specific provisions is essential in the absence of an appropriate state philosophy or when states abandon their philosophy for the sake of expediency.

For example, in addition to broadening the availability of Medicaid to fund a wider range of appropriate services, the "Chafee Bill" would require: appropriate placement close to home when consistent with the needs of the individual (when out-of-home community residential placement is made); equal access to community services without regard to prior residence or severity of disability; participation of parents or guardians in planning for community placement; due process when they disagree with placement or treatment decisions; and parent involvement in assessing the physical and social environment of residential settings for persons who are severely disabled. The "Chafee Bill" also contains provisions that would restrict the size of community residential facilities in order to create a more homelike environment. And finally, the "Chafee Bill" provides individuals and their families the right to choose from available licensed service providers.

Parent and family participation and involvement, equal access to services for all persons with developmental disabilities, and acknowledgement of the need of these persons who are disabled to be an integral part of their own community are essential elements of contemporary treatment philosophy. The "Chafee Bill" aptly incorporates all of these elements into the law of the land.

The Political Debate Over the "Chafee Bill"

The key players in the political debate over the "Medicaid Home and Community Quality Services Act" include the federal government, state governments, public employee representatives and advocates. These groups view the "Chafee Bill" in the context of its impact on their respective interests. Certainly, however, the fiscal consequences of this legislation for both the state and federal government are potentially profound. By definition, the Medicaid program is a financial program. It is self-evident, therefore, that the debate over the "Chafee Bill" will, in large measure, turn on the results of the fiscal impact of this legislation.

A. The Fiscal Perspective

The Medicaid program costs the federal government nearly 35 billion dollars annually. The developmental disabilities component of this program includes 10% of these costs or 3 7 billion dollars per year. These federal costs are, of course, state revenues. Legislation that potentially changes this financial relationship is of vital concern to both of these respective levels of government.

Clearly, the federal government's concern with respect to this issue is straightforward. The federal government's budget is in the midst of a deficit crisis of unprecedented proportion. Any legislation that potentially adds to that crisis must be viewed with understandable concern. While the "Chafee Bill" would cap institutional costs, which run nearly 2.5 billion dollars annually, it creates broad new entitlements for community-based services. In preliminary estimates, the Congressional Budget Office (CBO) claimed that this trade-off between institutional cost containment and additional community services entitlements would, in the short run, save the federal government money. However, CBO also maintained that the long-range consequences would be a relatively modest increase to the federal government of approximately 300 million dollars per year until 1992, at which time it is anticipated to stabilize.

The Executive Branch of the federal government, on the other hand, claims that Senator Chafee's legislation is a "budget buster". The Office of Management and Budget (OMB) claims that the "Chafee Bill" would, by 1992, cost the federal government an additional 1.29 billion dollars annually. According to OMB's analysis, any initial savings created by this legislation is more than lost through the establishment of new and broad entitlements.

In reality it is extremely difficult to determine which branch of the federal government, Executive or Legislative, is correct. Neither can predict the extent to which the new entitlements established by the "Chafee Bill" will be utilized. Further, any accurate analysis of the fiscal impact upon the federal government must ultimately rest upon an accurate analysis of what fiscal impact the "Chafee Bill" will have on the states. After all, it is the states that will claim federal Medicaid dollars based on the costs they experience operating institutions and structuring community-based entitlements under the

y definition, the Medicaid program is a financial program. It is self-evident, therefore, that the debate over the 'Chafee Bill' will, in large measure, turn on the results of the fiscal impact of this legislation."



he likely fiscal implications of the 'Chafee Bill' would undoubtedly accelerate the total growth of appropriate community-based service levels in New York State for persons with develop-



provisions of Senator Chafee's legislation. Such cost experience can in no way be uniform. Rather, it will vary from state-to-state and will depend on a variety of factors including each state's Medicaid matching ratio; whether a state opts to maintain existing levels of institutional services; the degree to which a state is willing to expand community-based entitlements; and the extent to which each state now pays for services on its own which, under the "Chafee Bill", would qualify for federal Medicaid dollars.

In New York State, for example, there are approximately 240 million dollars expended on services which are funded solely with State dollars and which appear to qualify as Medicaid eligible entitlements under the "Chafee Bill". It would seem, therefore, that if the "Chafee Bill" was currently in force, New York State could conceivably reduce its costs for those services by 120 million dollars (equivalent to the State's 50% Medicaid matching ratio) and reinvest its savings into additional Medicaid eligible services in order to comply with the maintenance of effort provision of the "Chafee Bill". The net result of these actions would mean that in New York State, each dollar which the State now spends on qualifying non-Medicaid eligible community-based services from non-federal funds would support two dollars of total expenditure under the provisions of the "Chafee Bill".

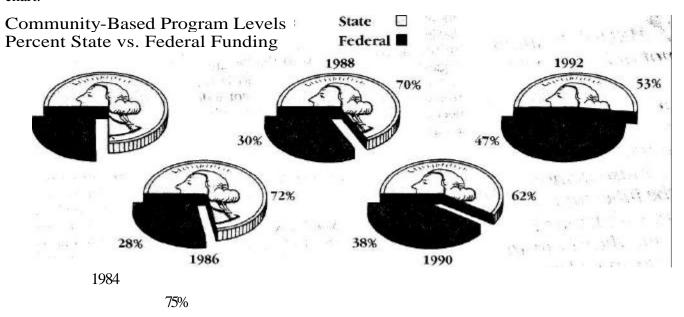
The following chart summarizes the fiscal impact of the "Chafee Bill" on New York State by service category:

Community-Based Services:
Fiscal Impact on
Current Non-Medicaid
Services

	Estimate of							
	Current "Chafee Eligible" Non-Medicaid State Expenditures	Under "Chafee" Required State Expend.	Under ''Chafee'' Avail. Federal Funds	Total Expend. With ''Chafee'				
Program (millio	ons)							
Day Services	\$100 ,	\$100	\$100	\$200				
Residential Serv.	\$110	\$110	\$110	\$220				
Family Spt. Ser.	\$ 20	\$ 20	\$ 20	\$ 40				
Other Serv.	\$ 10	\$ 10	\$ 10	\$ 20				
					\$240	\$240	\$240	

The likely fiscal implications of the "Chafee Bill" would undoubtedly accelerate the total growth of appropriate community-based service

levels in New York State for persons with developmental disabilities. Further, the proportion of federal funding for community-based services would substantially increase. Such increase is summarized by the following chart:



As the chart indicates, assuming that the "Chafee Bill" is enacted in 1988, program levels for appropriate community-based services would grow at an accelerated pace over prior year rates. Federal funds, which now support about 30% of community-based programs, would, under the "Chafee Bill", support almost 47% of total community-based program levels. Indeed, at least in New York State, the "Medicaid Home and Community Quality Services Act" would create an obvious incentive to expand community-based development; which is, of course, exactly the outcome which this legislation is intended to achieve.

Again, from a fiscal perspective, the position of each state on the "Chafee Bill" will vary according to the outcome of an analysis, like that for New York State, based on a unique set of circumstances. However, the fiscal perspective is not necessarily the overriding concern for any of the participants in the political debate over this bill.

B. Other Political Concerns

Despite what appears to be an overwhelming case for New York State to support the "Chafee Bill", the State's Office of Mental Retardation and Developmental Disabilities (OMRDD) is opposed to this legislation. This is a striking departure from an aggressive strategy which OMRDD has maintained for nearly a decade aimed at maximizing its federal Medicaid revenues. It further highlights the complexity of issues surrounding the political debate over federal legislation which can effectuate sweeping national changes without possibly being able to take into account the multiplicity of concerns experienced by each of the 50 states.

For example, a key concern of New York State continues to be the maintenance of a large and costly system of antiquated institutional care. This system consists of 19 developmental centers caring for approximately 10,000 individuals. It is plagued by client care problems and is the subject of persistent federal oversight activities. It currently costs \$271 per day to operate these centers for each resident served.



espite what appears to be an overwhelming case for New York State to support the 'Chafee Bill', the State's Office of Mental Retardation and Developmental Disabilities (OMRDD) is opposed to this legislation. This is a striking departure from an aggressive strategy which OMRDD has maintained for nearly a decade aimed at maximizing its federal Medicaid revenues."

MRDD's position only highlights political

problems caused by the unique circumstances not facing states in their individual

service systems; it also demonstrates the inherent inability of organizations to look beyond their immediate interests in order to seek the realization of a treatment philosophy which they have ostensibly been pursuing for over a decade."

While New York State has aggressively deinstitutionalized these facilities for over a decade its annual operating costs are almost 600 million dollars.

Clearly, New York State has a vast and continuing investment in its institutional operations. Thus, the freeze on reimbursement to facilities over 15 "beds" constitutes a substantial concern to OMRDD. In testimony submitted to the Senate Subcommittee on Health regarding the "Chafee Bill", OMRDD Commissioner Arthur Y Webb stated, "This freeze - which is not indexed for an individual state to accommodate union negotiations, fixed cost trends, most inflation, necessary capital improvements, or even the cost of deinstitutionalization - would constitute a real cut by the federal government."

In this respect, it should be noted that for a number of years, OMRDD has invested considerable time and effort developing its own "Medicaid Waiver" proposal which, like the "Chafee Bill", is intended to broaden the ability to use Medicaid funding for a broad array of community-based services. Though this proposal has never been sufficiently defined to facilitate a clear comparison with the "Chafee Bill", it has been developed by New York State and presumably for New York State. Unlike the "Chafee Bill", it does not represent a sweeping change in national Medicaid policy over which New York State has relatively little control or assurance that its concerns will be taken into account.

OMRDD's position not only highlights political problems caused by the unique circumstances facing states in their individual service systems; it also demonstrates the inherent inability of organizations to look beyond their immediate interests in order to seek the realization of a treatment philosophy which they have ostensibly been pursuing for over a decade. Thus, it is not surprising that OMRDD's concern over the freeze on reimbursement to facilities over 15 "beds" is shared by public employee unions across the nation, who have a vested interest in maintaining these large facilities within which so many of their members are employed.

Strong public employee opposition to the "Chafee Bill" was evident at hearings held on the bill last March. Mr. Jerry Klepner, the Director of Legislation for the American Federation of State, County and Municipal Employees (AFSCME), stated that large institutions are "the backbone of services to the mentally retarded." He added that the bill would both undermine that care and give too much power to the states regarding quality assurance issues. As a result, more persons who are disabled would be cared for in a greater number of non-public community-based facilities offering inferior care to that generally rendered in state-operated programs. As evidence, Mr. Klepner cited a recent study done in Philadelphia, claiming that in some 200 privately operated residences in Pennsylvania, 83% of clients lacked adequate services.

Also opposing the bill at the Senate hearings was Dr. W. Robert Curtis, Associate Professor at the New School for Social Research in New York. Dr. Curtis stated that the bill would eliminate a "150 year-old covenant" between government and its citizens. He described the covenant as an understanding that "the state" would "take over the care of persons in dire straits" and exercise its judgment with

respect to their care, treatment and well-being. He further added that the "Chafee Bill's" incentive for deinstitutionalization would create movement of such persons out of public institutions and into unstable privately operated settings. Such movement would place the well-being of persons with developmental disabilities in the hands of "unelected and unaccountable private operators", according to Dr. Curtis, who are primarily motivated by economic factors rather than a concern for client care.

Clearly, for one reason or another, the rallying point for opponents of the "Chafee Bill" is the freeze on federal funding to large facilities. Yet it is on just this point that proponents of this legislation are in greatest agreement. Again, at the Senate hearings, Mr. K. Charles Lakin, a noted national expert on developmental disabilities, began the hearings by stating that though most major federal legislation dealing with disabilities, such as the Developmental Disabilities Act, is based on a philosophy of community-based care, 85% of persons with developmental disabilities still reside in facilities over 15 "beds". Mr. Lakin noted that community-based care improved individual functional capacity of persons who are disabled, was more cost effective and more humane than institutional care. He concluded by stating that there "is no purpose for institutionalization in this day and age".

NYSARC, of course, as a strong advocate, agrees with much of Mr. Lakin's testimony. From our perspective, this bill seeks to alter the status quo; an activity which we observe based on our own experience, inevitably engenders powerful opposition. Thus, we see the political debate over the "Medicaid Home and Community Quality Services Act" as one in which entrenched viewpoints and interests become threatened and respond accordingly; a response that is very often the trademark of truly meaningful change and landmark legislation.

learly, for one reason or another, the rallying point for opponents of the 'Chafee Bill' is the freeze on federal funding to large facilities. Yet it is on just this point that

proponents of this legislation are in greatest reagreement."

ersons with developmental disabilities are best served in the community through the delivery of a broad range of services."... "the 'Chafee Bill' would finally

reconcile this philosophy with the Medicaid funding system; a system that must be overhauled if our national goals for these individuals are to be finally and fully realized."

Conclusion

The "Chafee Bill" clearly advances long sought after improvements in the manner in which Medicaid funding is used to provide services to persons with developmental disabilities. As stated, this legislation would enhance the ability to tailor services to the needs of individuals by making Medicaid dollars available to fund a broad array of community-based services. Under current law, Medicaid dollars are limited to intensive services that are not always appropriate for the needs of many persons who are mentally retarded. As a result, Medicaid creates an incentive to serve many persons in overly intensive or restrictive settings or to not serve them at all.

Further, the "Chafee Bill" includes provisions aimed at encouraging states to minimize their reliance on institutional care for persons with developmental disabilities. As an Association, we have embraced this precept and advocate for the right of each individual to live as normal a life as possible in community-based settings.

Additionally, the "Chafee Bill" would not only broaden the array of services available to persons with developmental disabilities, but it would also increase the quantity of such services. Under the provisions of this bill, in excess of 200 million dollars worth of services which are now fully funded by New York State would become eligible for federal matching funds through the Medicaid program.

Finally, a key concern for many interested parties, including New York State, has been the "Chafee Bill's" proposed freeze of Medicaid funds to facilities over 15 persons. In certain states this provision could require acceleration of the pace of deinstitutionalization in order to eliminate costs that might be incurred at developmental centers in excess of the freeze-imposed cap. Acceleration of deinstitutionalization could further deny placements to persons living at home and could aggravate quality of care concerns at facilities targeted for closure.

However, New York State is already aggressively deinstitutionalizing its developmental centers. Costs in these facilities have been dropping. Consequently, we believe that there is little likelihood that the "Chafee Bill" will cause New York State to further accelerate the movement of individuals out of developmental centers and to experience the problems that would accompany such acceleration.

Nevertheless, our organization, like many others, is concerned with various technical aspects of the "Chafee Bill" (see Appendix I, "Analysis of Specific Concerns") and we will continue to work to ameliorate these concerns. However, the "Chafee Bill" reflects the philosophy of the overwhelming majority of experts and advocates in the field of developmental disabilities: that persons with developmental disabilities are best served in the community through the delivery of a broad range of services. We maintain that the "Chafee Bill" would finally reconcile this philosophy with the Medicaid funding system; a system that must be overhauled if our national goals for these individuals are to be finally and fully realized.

Appendix I Analysis of Specific Concerns

The following is an analysis of various concerns which NYSARC and New York State's Office of Mental Retardation and Developmental Disabilities (OMRDD) have identified in the "Medicaid Home and Community Quality Services Act".

ISSUE: Does the bill prohibit Medicaid reimbursement for capital construction costs associated with the development of community living facilities?

NYSARC ANALYSIS

OMRDD ANALYSIS

The "Chafee Bill" amends Title XIX of the Social Security No federal Medicaid for capital construction costs Act, from which funding for the ICF/MR is derived.

The bill is "silent" on the issue of capital reimbursement, it does not explicitly provide for such reimbursement nor does "Chafee Bill" disallows federal Medicaid for capital costs it prohibit capital reimbursement.

The current Title XIX is also silent on the issue of capital reimbursement.

Currently, up front costs for capital construction are met through State grants, bank financing, sale of bonds, States would have to pay for capital construction and private leasing; there currently are no federal capital major renovation costs. grant programs for ICF/MR capital construction costs.

Senator Chafee indicates the bill would continue to provide federal reimbursement for capital costs through reimbursement of building depreciation and mortgage interest or fair market rent.

associated with establishing and operating small community living facilities.

associated with small community living facilities.

Up front capital expenditures are not shared by the federal government under the "Chafee Bill".

ISSUE: The bill imposes a limitation on payments for services provided in large ICF/MRs and Skilled Nursing Facilities.

NYSARC ANALYSIS

OMRDD ANALYSIS

Creates strong incentives for acceleration of pace of deinstitutionalization to avoid increase in state share cost of institutional services.

Creates strong incentives for "Medicaiding" certain community services (e.g., community residences, family support, vocational rehabilitation services) to offset loss of federal reimbursement for institutional service cost increases which exceed base year cost.

Provides for increase in federal reimbursement during any year in which CPI inflation exceeds 6% (onlyexcess over 6% additionally reimbursed). Provides for increases in federal reimbursement to cover costs attributable to implementation of an approved reduction plan.

Amendment establishes freeze on maximum federal reimbursement payable to states for developmentally disabled people living in ICF/MRs with 16 or more

Freeze or capped amount is not indexed for states to accommodate union negotiations, fixed cost trends, most inflation, necessary capital improvements or the cost of deinstitutionalization.

Constitutes dangerous precedent by limiting a Medicaid entitlement.

Limitation on payment aspect of bill exceeds positive aspects of the bill.

ISSUE: Medicaid Entitlement

NYSARC ANALYSIS

The bill imposes a freeze on Medicaid reimbursement for large facilities. The federal government currently has authority to impose upper limits on payments for certain Medicaid services, e.g. cost of medications. ICF/MRs, etc., therefore, no precedent would be set by the "Chafee Bill".

While the bill would limit or infringe upon an entitlement - institutional care - it would establish new community service entitlements and authorizes states to establish many additional community service entitlements at their discretion.

OMRDD ANALYSIS

The freeze on federal reimbursement for large facilities sets a dangerous precedent on the issue of Medicaid entitlement.

The bill opens up community services to families caring for persons who are disabled living at home.

The "Chafee Bill" provides a much broader array of services that could potentially drive Medicaid reimbursement.

ISSUE: The "Chafee Bill" disallows reimbursement for room and board costs.

NYSARC ANALYSIS

OMRDD ANALYSIS

The bill limits Medicaid reimbursement for room and boa costs to those extraordinary costs of food or housing attributable to the disabling condition of individuals served.

Currently, Community Residences receive SSI provider payments which pay a portion of room and board costs. The federal share of SSI is \$554 per person per month; the State share is \$370 upstate and \$400 downstate.

Amendments should be sought to ensure that extraordinary food and housing costs attributable to the disabling condition and the high cost of living of certain geographical locations is reimbursable under the bill.

The bill limits Medicaid reimbursement for room and board The bill prohibits funding for room and board costs costs to those extraordinary costs of food or housing for small community residential programs.

Currently, Medicaid pays for all room and board costs associated with the operation of ICF/MRs.

ISSUE: Under the "Chafee Bill", could the State continue to build or obtain funding increases for Small Residential Units (SRUs) located on the grounds of developmental centers operated by the State?

NYSARC ANALYSIS

OMRDD ANALYSIS

The bill encourages the development of small community living facilities located in residential neighborhoods populated primarily by non-disabled individuals.

Size of new facilities would be limited to 3x the average family size in the area in which the facility is located per the 1980 decennial census.

The bill provides for federal reimbursement as "community living facilities" for those facilities 15 persons or less, which do not increase in size after the bill's enactment.

Reimbursement for clusters of up to three facilities with up to eight residents per SRU would be allowable.

The bill would not provide reimbursement for new SRUs unless they were located in a residential neigh borhood for non-disabled individuals, which would be very unlikely.

The State loses the ability to build SRL's.

ISSUE: The bill broadens the eligibility requirements for individuals to receive services by substituting criteria approved in the New York State Medicaid Plan with the SSI eligibility criteria contained in Section 1614(3) of the Social Security Act; the bill would increase the age of onset of disability criterion by one year, up to age 50, during each succeeding year after enactment.

NYSARC ANALYSIS

OMRDD ANALYSIS

The impact of this provision is difficult to determine.

ft seems to allow Medicaid reimbursement for persons who become mentally ill prior to the age of onset limit established by the bill (currently 18 years of age under New York State law.)

The bill could conceivably make certain individuals who are homeless and disabled eligible for services.

The bill could create competition among State agencies for Medicaid funding.

The bill liberalizes the use of Medicaid funding for individuals who will likely receive increased attention and services from New York State with or without enactment of the "Chafee Bill".

The impact of increasing the age threshold annually is unknown.

New York State Association For Retarded Children, Inc.

393 Delaware Avenue Delmar, NY 12054 (518)439-8311

Local Chapters

J.N. Adam Developmental Ctr. New York City

Albany Niagara Allegany Oneida Benevolent Society Onondaga Bronx Developmental Center Ontario Broome-Tioga Orange Cattaraugus Orleans Cayuga Oswego Chautauqua Otsego Chemung Putnam Chenango Rensselaer Clinton Rockland

Columbia Rome Developmental Center

Community League-Wassaic D.C. St. Lawrence Cortland Saratoga Delaware Schenectady Dutchess Schoharie Frie Schuyler Essex Seneca Franklin Steuben Fulton Suffolk Genesee Sullivan

Greene Syracuse Developmental Center

O.D. Heck Developmental Ctr.

Herkimer

Tompkins
Ulster

Jefferson Warren-Washington

Lewis Wavne

Livingston-Wyoming Welfare League-

Madison

Monroe

Montgomery

Letchworth Village West Seneca

Developmental Center Westchester

Wilton Developmental Center

windin Developmental Cent

Nassau Yates

Newark Developmental Center

David B. Lettnum President Marc N. Brandt *Executive Director*



New York State Association For Retarded Children, Inc. 393 Delaware Avenue Delmar, NY 12054 (518)439-8311